siyam'kela

measuring hiv/aids related stigma

A report on the fieldwork leading to the development of HIV/AIDS stigma indicators and guidelines

Siyam'kela

*Siyam'kela [**SI-YUH-MU-GE-LAR**] is an African word from the Nguni language. Translated it means "We Are Accepting" expressing a collective embracing, understanding and acceptance of a challenge at a particular time. The word has thus been interpreted as "Together We Stand" for this project.*
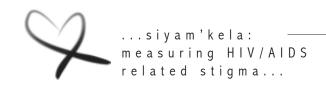
The Project has been designed to explore HIV-related stigma, an aspect of the HIV/AIDS epidemic, which is having a profoundly negative effect on the response to people living with, and or affected by HIV/AIDS. Within the context of the Project, Siyam'kela denotes a collective approach in working towards reducing HIV/AIDS related stigma and discrimination.

The Project has been designed to explore HIV/AIDS stigma, an aspect of the HIV/AIDS epidemic, which is having a profoundly negative effect on the response to people living with, and or affected by HIV/AIDS. Within the context of the Project, Siyam'kela denotes a collective approach in working towards reducing HIV/AIDS stigma and discrimination.

***Please note:** In describing the fieldwork this report uses certain terms to describe participants. These terms are offensive to some as they are reminiscent of racial classification terms used in the apartheid era. Nevertheless we have retained them to indicate our attempts to interview as diverse a range of South Africans as possible and to reflect the relationship between race and HIV/AIDS stigma. Race and racism are ongoing themes in post-apartheid South Africa and race classification is still used by the current South African government, for example in legislation around employment equity targets, to show progress in redressing imbalances of the past.*

The terms are not rigid categories but for the purposes of clarity we have adopted the following definitions: the term "black" refers to African, Coloured and Indian South Africans; the term "African" refers mainly to black South Africans of indigenous origins; "Coloured" refers mainly to black South Africans of mixed descent, "Indian" refers mainly to black South Africans of Asian descent and "White" refers mainly to South Africans of European descent.

It is important to note that participants in the study may have their own idiosyncratic interpretation of these terms.

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December 2003

A joint project of the:

- POLICY Project, South Africa;
- Centre for the Study of AIDS, University of Pretoria;
- United States Agency for International Development (USAID); and
- Chief Directorate: HIV, AIDS & TB, Department of Health

Researched by:

- Insideout Research

Supported by:

- Representatives from the *Siyam'kela* Reference Groups

Acknowledgments

This project has drawn expertise from individuals representing the following organisations:

AIDS Law Project

Centre for AIDS Development, Research and Evaluation (CADRE)

Chief Directorate: HIV, AIDS and TB, Department of Health

Department of Correctional Services

Department of Public Service and Administration (DPSA)

Faith Organisations in HIV/AIDS Partnership (FOHAP)

HOPE worldwide

Human Sciences Research Council of South Africa (HSRC)

Interdepartmental Committee on HIV and AIDS (IDC)

National Association of People Living with HIV/AIDS (NAPWA)

Positive Muslims

Southern African Catholic Bishops' Conference

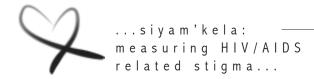Soweto HIV/AIDS Counsellors' Association (SOHACA)

Department of Statistics South Africa

The Anglican Church

Tsabotsoso

United Nations Development Programme (UNDP) – Greater Involvement of People Living with HIV/AIDS (GIPA) Project

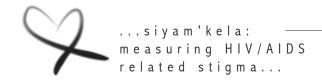University of Pretoria, School of Health Systems and Public Health

Contents

1. Introduction

The *Siyam'kela* Project is a joint endeavour of the POLICY Project, the Centre for the Study of AIDS at the University of Pretoria, the United States Agency for International Development (USAID), and the Chief Directorate: HIV, AIDS and TB, National Department of Health. Siyam'kela is an African word meaning 'we are accepting', expressing a collective embracing. The word has been interpreted as 'together we stand' to symbolise unity in challenging HIV/AIDS-related stigma.

Stigma, 'a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons'[1], can be **felt** (internal stigma), leading to an unwillingness to seek help and access resources, or **enacted** (external stigma), leading to discrimination on the basis of HIV status or association with someone who is living with HIV/AIDS.

Because stigma has an impact on prevention and care it is important to address it directly. However stigma-mitigation practice has not been well informed by theory and research. An urgent need was identified for indicators of stigma, which can be used to develop interventions and measure their success.

The *Siyam'kela* Project thus aims to pave the way for a stigma-mitigation process by developing **well-researched indicators** of HIV/AIDS-related stigma and discrimination. The Project has focused on three key areas essential to South Africa's response to HIV/AIDS:

■ faith-based organisations and communities as important sources of support to people living with HIV/AIDS (PLHAs)

■ government departments as workplaces committed to dealing with stigma through good policy and practice

■ the relationship between PLHAs and the media as an example of how empowered individuals can impact positively on perceptions and attitudes towards HIV/AIDS.

A comprehensive literature review, two consultative workshops and the establishment of reference groups in the focus areas of the Project ensured that a diverse range of opinions and experiences were reflected. The use of an independent research organisation, Insideout, for the fieldwork, also brought in a fresh perspective.

The Project consists of **six aspects**:

■ a **literature review** to provide a theoretical understanding of stigma

■ a **qualitative exploration of stigma experiences and perspectives** through focus-group discussions and key informant interviews across South Africa

■ the development of **indicators of internal and external stigma** through this fieldwork and in consultation with experts in the field

■ a **media scan** to contextualise and locate the fieldwork in a particular time and place

■ the documentation of **'promising practices'** which mitigate HIV/AIDS stigma

■ the development of **guidelines** to assist those who wish to develop interventions to impact positively on HIV/AIDS stigma.

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[1] Canadian HIV/AIDS Legal Network. (1998). *HIV/AIDS and Discrimination: A Discussion Paper.* Ottawa, Canadian HIV/AIDS Legal Network and the Canadian AIDS Society.

2. Method

| Literature review | ⇨ | **Consultative workshop**
Development of draft indicators |

⬇

Reference group meeting

⬇

| **Examining HIV/AIDS stigma in the South African media:**
January – March 2003 | ⇦ | **Reference group meeting** |

⬇

Data collection: Stigma experiences and perspectives

Focus groups:

- 9 PLHA media focus groups
- 9 faith-based focus groups (3 with faith leaders, 3 with congregation members; 3 PLHAs)
- 5 national government focus groups (3 with employees of various levels, 1 with union representatives, 1 with HIV/AIDS co-ordinators)

Interviews:

- 8 director-generals of participating departments
- 3 PLHAs working within national government

| Promising Practices | ⇦ |

⬇

Consultative workshop

- Feedback of findings
- Reworking of indicators and development of draft guidelines

⬇

Quality control

7 Key HIV/AIDS experts' input

⬋   ⬊

| **HIV/AIDS stigma indicators: A tool to measure HIV/AIDS stigma mitigation programmes** | **Tackling HIV/AIDS stigma: Guidelines for developing HIV/AIDS-supportive environments** |

2.1 Overview

The focus of this report is on:

■ the findings that informed the development of indicators for internal and external stigma

■ the findings that informed the development of guidelines to assist those who wish to develop interventions to reduce HIV/AIDS stigma

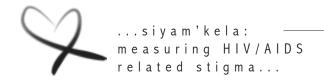■ the qualitative exploration of stigma experiences and perceptions in focus groups.

Two key project reports, namely the report on indicators and the government workplace guidelines, were developed based on the findings reflected in this report. The following *Siyam'kela* reports are available[2]:

■ *HIV/AIDS-related stigma: A literature review*

■ *Examining HIV/AIDS stigma in selected South African media: January – March 2003: A summary*

■ *HIV/AIDS stigma indicators: A tool for measuring the progress of HIV/AIDS stigma mitigation*

■ *Tackling HIV/AIDS stigma: Guidelines for the workplace*

■ *Tackling HIV/AIDS stigma: Guidelines for people living with HIV/AIDS who interact with the media*

■ *Tackling HIV/AIDS stigma: Guidelines for faith-based organisations*

■ *Promising practices of stigma mitigation efforts from across South Africa: Reflections from faith-based organisations, people living with HIV/AIDS who interact with media and HIV/AIDS managers in the workplace*

The **collection of HIV/AIDS stigma experiences and perceptions** involved a group of 182 participants who participated in 23 focus groups (conducted across all nine provinces of South Africa) and 11 in-depth interviews. The purpose of the fieldwork was to collect a wide range of experiences of HIV/AIDS stigma in order to develop indicators that would enable the measurement of the progress of stigma-mitigation projects. In addition, seven telephonic interviews were held with key HIV/AIDS experts as a means of quality control.

The experiences of representatives from three sectors, namely faith-based organisations, government workplaces and PLHAs who had had experience of interacting with the media, were collected during focus-group discussions. These three sectors were specifically chosen as they were considered to represent institutions which people look to for leadership, and they are also institutions that have the power to shape people's perceptions and responses. To capture the complexity of HIV/AIDS stigma, a qualitative exploration of experiences of HIV/AIDS in these three sectors was conducted. A focus group approach was viewed as most appropriate as it allows participants to explore the perceptions and experiences of HIV/AIDS stigma through discussion.

An effort was made to ensure that the participants were representative of the South African population by organising focus groups in all nine provinces and targeting both men and women from all race groups. Of the focus-group participants, 85% were Black, 55% were women and 43% were people living with HIV/AIDS. The number of participants in the groups varied, ranging from 4 to 12 participants. Participation was voluntary, but participants were given money to cover their transport costs.

The data collected through the interviews and focus groups was used to refine the draft **indicators** and to develop **guideline documents** for the development of stigma-mitigation interventions for the three sectors.

2.2 Overall approach

A participatory, consultative approach informed all aspects of the research. The project established four reference groups: three of the reference groups consisted of representatives of the three selected sectors

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[2] *A copy of all Siyam'kela documents can be found at http://www.policyproject.com/siyamkela.cfm or http://www.csa.za.org*

and the fourth consisted of a group of experts with broad HIV/AIDS experience. The reference groups offered guidance and support for the overall project and facilitated partnerships with collaborating institutions. Each reference group held five meetings during the study period and e-mail correspondence was ongoing.

	National Reference Group	Faith Reference Group	Media and PLHA Reference Group	National Government Reference Group
1st meeting	17/09/2002	20/09/2002	31/10/2002	19/09/2002
2nd meeting	19/11/2002	21/11/2002	3/12/2002	20/11/2002
3rd meeting	14/03/2003	20/03/2003	1/03/2003	13/03/2003
4th meeting	27/06/2003	19/06/2003	27/06/2003	27/06/2003
5th meeting	25/11/2003	27/11/2003	25/11/2003	25/11/2003

Two consultative workshops were held. The first consultative workshop was held in November 2002 to develop draft indicators. Eighteen representatives participated, including representatives of the CSA, the POLICY Project, the four reference groups and a number of AIDS experts. The second consultative workshop was held in July 2003 to present the draft indicators and guidelines to the stakeholders who participated in the first workshop and to collect their input in order to refine the documents.

2.3 Endorsement

The project needed to obtain endorsement for the study from representatives of all three sectors.

The relevant national and provincial heads of Christian faith groups, which included the Catholic, Anglican, Methodist, Uniting Presbyterian and Dutch Reformed faith groups, were approached to endorse the study and asked to identify possible faith leader participants as well as faith leaders who could be approached to identify congregation members in each of the provinces. The Muslim Judicial Council and an HIV/AIDS community-based organisation, Positive Muslims, were approached as representatives of the Islamic faith to endorse the study.

With the support of the chief director of the Chief Directorate: HIV, AIDS and TB in the National Department of Health, the *Siyam'kela* Project obtained the necessary endorsement from the Department of Public Service and Administration (DPSA). The DPSA requested relevant departments to make themselves available to participate in the project. The project also received support from the government's Interdepartmental Committee on HIV and AIDS and USAID/South Africa.

The National Association of People Living with HIV/AIDS (NAPWA) also gave its endorsement and provided support to the project by inviting PLHAs in each of the nine provinces to attend focus-group discussions.

2.4 Selection of participants

2.4.1 Media

The first focus area of this study was PLHAs who had had experience of interacting with the media. The AIDS Consortium, the Treatment Action Campaign (TAC) and NAPWA were approached to find participants for these groups. In total, nine PLHA focus groups were held, one in each province. An effort

was made where possible to have gender-specific and race-specific groups, but this was not always possible. The only criterion for participation was that the person living with HIV/AIDS had previously interacted with the media. Between 10 and 12 participants attended the focus groups in each province.

2.4.2 Faith sector

Within the faith sector nine focus groups were held, one in each of the nine provinces. The research focussed on three sub-groups within the faith sector, namely faith leaders, congregation members and PLHAs who belonged, or used to belong, to a faith group. In some cases faith leaders (from both the Christian and Islamic faiths) were not ordained leaders but rather opinion leaders. Opinion leaders were lay persons belonging to a faith-based organisation who were responsible for conducting various HIV/AIDS initiatives within their congregations. The opinion leaders who participated in the focus groups had a deep level of understanding of issues related to HIV/AIDS. They had a strong influential voice about HIV/AIDS issues within the structures of their faith-based organisation.

Three focus groups were conducted within each subgroup. Participants were drawn from the Christian faith (including the Catholic, Anglican, Methodist, Uniting Presbyterian and Dutch Reformed churches) and the Islamic faith, as according to the 1996 South African census, these faith groups represented the majority of the South African population. The African Zionist faith group, which also has a large membership in South Africa, was also targeted. However, the researchers were unable to find any participants for the study from this group.

Faith leaders identified congregation members to participate in focus groups. NAPWA provincial offices, Positive Muslims and the Islamic Careline identified PLHA participants for the faith focus groups. The Muslim Judicial Council, Positive Muslims and the Islamic Careline were approached to identify Muslim clergy who might be interested in participating and also to nominate possible congregation members to participate in the study. However, only Positive Muslims and the Islamic Careline responded by identifying faith leaders, congregation members and Muslim PLHA participants countrywide.

2.4.3 Government workplace sector

National government was selected as an example of a workplace setting. Three focus groups were held with employees from different levels within the public sector, namely levels 1-5[3], levels 6-8 and levels 9-12. The two remaining groups were held with representatives of the National Education, Health and Allied Workers' Union (NEHAWU) and with national government HIV/AIDS co-ordinators. All government

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[3] Level 1: Cleaners
Level 2: Cleaners 2 and clerks grade 1
Level 3: Secretaries, clerks grade 2
Level 4: Senior secretaries grade 1, senior clerks grade 1
Level 5: Senior secretaries grade 2, senior clerks grade 2

Level 6: Senior secretaries grade 3, senior clerks grade 3
Level 7: Administration officers, planners
Level 8: Senior administration officers, senior planners

Level 9: Assistant directors first leg, principal planners
Level 10: Assistant directors second leg, chief planners
Level 11: Deputy directors first leg
Level 12: Deputy directors second leg

Level 13: Directors
Level 14: Chief directors
Level 15: Deputy director-generals
Level 16: Director-generals

The terms grade and leg refer to experience, years of service and qualifications.

departments were invited to participate in the study. An effort was made to include representatives from each of the participating departments in each workplace focus group, including Agriculture, National Treasury, the Presidency, the Public Service Commission, the South African Police Service, Land Affairs, Correctional Services, Housing, Justice, Arts and Culture, Science and Technology, and Social Development. See Appendix 1 for a detailed breakdown of the participation of departments.

In addition to the focus groups, eight in-depth interviews were conducted with director-generals – or their nominated representatives – from the participating departments. Four key informant interviews were conducted with PLHAs working in different government departments.

The Interdepartmental Committee on HIV and AIDS (IDC) was invited to participate (in the HIV/AIDS co-ordinator focus group), and it assisted in identifying and inviting focus-group participants from the three employee levels. Union representatives were identified through the national NEHAWU office, while the United Nations Development Programme's (UNDP) Greater Involvement of People Living with HIV/AIDS (GIPA) Project provided the contact details of people placed in national government in terms of GIPA who would be willing to participate in the study. All director-generals of the participating departments were invited to participate in the study. Some elected representatives to meet with the research team for an interview.

2.5 Measurement tools

2.5.1 Discussion guides

Discussion guides were developed for each of the three sectors and their respective sub-groups.

As an icebreaker, all focus groups were asked to play a word association game with the words 'cancer', 'heart attack' and 'HIV/AIDS'. They were also challenged with the question as to whether there are 'innocent' and 'guilty' people living with HIV/AIDS, as well as how HIV/AIDS spreads.

Workplace, faith leadership and congregation members were asked whether – and to what extent – they would disclose their status if they were HIV positive in their respective social settings.

Services and support, as well as the key messages about HIV/AIDS in the respective social settings were discussed.

PLHA participants were asked about their experiences of HIV/AIDS stigma, as well as their experiences of interacting with the media.

2.5.2 Interview schedules

Interview schedules were developed for the various interviews:

- The interview schedule for the director-generals – or their representatives – was structured. It focused on HIV/AIDS policies and HIV/AIDS programmes in place, how they are being implemented and monitored, as well as the kinds of formal HIV/AIDS messages produced in the workplace. Stigma questions focused on disclosure and the perceived extent of stigmatisation within the department. Participants were also asked how policies could address HIV/AIDS stigma.
- The interviews with the PLHA employees working for national government departments were based on the focus-group discussion guides which explored their experiences of HIV/AIDS stigma and the extent to which their working environment supported them.
- The quality control interview schedules were open-ended with the aim of exploring feedback from the participating experts after they had reviewed the draft indicator and guideline documents.

2.6 Data collection

All focus-group participants and interviewees were required to sign consent forms. The focus-group discussions and interviews were tape recorded and transcribed. Participants were allowed to speak in their own languages in focus groups, since either the facilitator was fluent in their language or another participant was able to translate. The transcribers would then translate the discussions where necessary.

2.6.1 Media and PLHA sector

A total of 59 PLHAs (23 females and 36 males) in the nine focus groups shared their experiences of interacting with the media. Focus groups were held in each of the provincial capitals: Cape Town, Port Elizabeth, Kimberley, Bloemfontein, Durban, Nelspruit, Polokwane, Mafikeng and Johannesburg. Transport costs were covered, allowing participants to travel to these centres where necessary. The research team struggled to identify and invite White and Coloured participants, as White and Coloured PLHAs tend not to openly disclose their status or belong to an association or organisation. The snowball technique was used to include these groups, even though the networks were limited. As a result only 10% of the PLHA participants were White. An effort was made to keep the focus groups homogenous with regard to race and gender so that participants could feel free to comment honestly on their experiences of HIV/AIDS stigma and to explore how race and gender may impact differently on their experiences. The criterion of having interacted with the media also made it difficult to locate a sufficient number of participants of only one gender in each of the provinces. As a result it was only possible to hold male-only focus groups in Durban and Johannesburg. All other focus groups were mixed with regard to gender. The facilitators did, however, make a conscious effort to explore possible gender differences in the focus groups by asking participants if experiences were different for men and women.

2.6.2 Faith sector

A total of 25 faith leaders, 31 congregation members and 20 PLHA congregation members participated in the focus groups. Three focus groups were held in Kimberley, Johannesburg and Cape Town with a total of 25 faith leaders (9 females and 16 males). Of the participants, seven were White, three Coloured and two Indian. Another three focus groups were held with a total of 31 members of faith congregations in Polokwane, Mafikeng and Port Elizabeth (26 female and 5 male congregation members). All participants in these groups were Black. In addition, a total of 20 PLHAs (16 females and 4 males) shared their experiences of faith communities in three focus groups held in Durban, Bloemfontein and Nelspruit. Again, all of the PLHA participants were Black. Of the three focus groups two were all-female groups.

It should be noted that the Islamic faith was not consistently represented in all focus groups. In total only two Muslim faith leaders and opinion leaders, two Muslim PLHAs and one Muslim congregation member attended the focus groups.

2.6.3 Government workplace sector

A total of 12 level 9-12 employees, 11 level 6-8 employees, 11 level 1-5 employees, 10 HIV/AIDS co-ordinators and 3 union representatives participated in these focus groups. Of the 47 participants who attended, 26 were female and 21 male. Participants belonged to the following race groups: White (11), Coloured (3), Indian (2) and Black (31).

Ten union representatives were invited and confirmed their attendance, but only three attended the focus group. The research team also had some difficulty in running the planned focus group with national government employees living with HIV/AIDS. There are very few PLHAs within national government who have openly disclosed their status, with only five GIPA placements, not all of whom were available

to participate. A focus group was scheduled with GIPA placements. However, none of the identified employees were able to attend the focus groups as scheduled. Telephonic interviews were instead held with three of the four targeted PLHA participants to ensure that PLHAs within the workplace were given a voice.

Not all interviews with director-generals could be conducted as some director-generals were unavailable or did not respond in time to be included in the data collection process. Eight out of ten planned in-depth interviews were conducted with director-generals or their nominated representatives in the following departments:

- Department of Correctional Services: deputy director-general
- Department of National Treasury: (three persons attended the interview) director of AIDS/wellbeing, the person responsible for social responsibility internally, and the general manager: human resources.
- South African Police Service: director of social services
- Department of Public Service Commission: chief director
- Department of Science and Technology: general manager: human resources
- Department of Land Affairs: director of transformation and HIV/AIDS manager
- Department of Justice: director-general
- Department of Agriculture: (two persons attended the interview) deputy senior manager: human resources, and senior manager: human resources.

2.7 Analysis

The focus groups held in each of the three sectors (faith groups, media and national government workplace) were analysed separately. Each of the sub-sectors within these sectors were also analysed separately. In the faith focus groups, faith leaders, congregation members and PLHA members of faith groups were therefore analysed separately. Similarly, in the workplace focus groups, senior managers, middle managers, junior managers, HIV co-ordinators, and union representatives were analysed separately. Once themes emerged, the various sub-sectors were analysed for their differences and similarities.

Content analysis was used to analyse the transcripts. All information was analysed in terms of emerging themes. Common patterns were identified and categories grouped into broad emerging themes, which were then grouped into sections, related to environment, internal and external stigma, and perceptions of HIV/AIDS. The research team cross-checked the analysis to verify the categories and sub-categories.

Based on the findings, draft indicators to measure external and internal HIV/AIDS stigma, and draft guidelines for stigma-mitigation interventions were developed. Special attention was given to issues of gender and race in the analysis.

2.8 Quality control

Participants for the quality-control interviews were selected based on their HIV/AIDS expertise.

The preliminary indicators and guidelines were sent to the interviewees prior to the telephonic interview for review. Seven telephonic interviews were held with HIV/AIDS experts to discuss the preliminary indicators and guidelines which emerged from the focus group findings. Ten participants were identified and contacted for a telephonic interview but only seven were able to provide input.

Interviewees included two PLHAs, one member of a faith-based organisation, one government official, two HIV/AIDS specialists with broad experience, and one HIV/AIDS gender expert.

In addition, two representatives of faith groups, one person from national government and one HIV/AIDS

specialist with broad experience provided written feedback on the draft guidelines and indicators respectively.

2.9 Limitations

Despite the efforts to invite participants who would be demographically representative, the majority of PLHA participants were African, with no representation from Coloured or Indian groups and only a handful of White representatives. Focus groups were held in the provincial capitals. In an effort to also include participants from rural areas, group members were not turned away even if they had to travel from outlying areas. Some participants travelled between 180 and 200 kilometres to attend a focus group. Racial and gender representation was limited to those who were available and willing to participate in the study.

Participants were selected through the help of people within their organisations (for example, faith leaders, HIV/AIDS co-ordinators or NAPWA staff) and as a result people who were actively involved in the HIV/AIDS field were more likely to participate. The findings can therefore not be generalised to average South Africans not working in the HIV/AIDS field.

3. Indicator findings – general

3.1 Perceptions of HIV/AIDS

Stigma affects men, women and different race groups differently. The perception of HIV/AIDS as a woman's disease and as an African disease emerged in the focus groups. These perceptions can influence the way in which PLHAs perceive and interpret HIV/AIDS stigma.

3.1.1 Perception of HIV/AIDS as a woman's disease

Participants mentioned the perception of HIV/AIDS as a women's disease. This was mainly as a result of antenatal services in the public sector routinely testing pregnant women, with their consent, for STIs (including HIV). Since women access these services, it is they who discover their HIV-positive status first and who then have the burden of sharing the information with their male partners. More specifically, HIV/AIDS is perceived to be an African women's disease as private hospitals do not routinely test pregnant women for HIV and it is usually African women who access public health care services.

3.1.2 Perception of HIV/AIDS as an African disease

Participants made mention of the perception of HIV as a African disease as well as the apparent apathy in other communities, especially the white community:

'We still have the division in South Africa that AIDS is a black thing, so it won't come to me. You know, in the White community we find ourselves in a difficult situation of not accepting, and of thinking that this is a black thing.'

Level 9-12 female government employee

'The racial issue has an impact on the AIDS issue in the sense that there is this thing among the whites that AIDS is a black thing.'

Level 9-12 male government employee

As mentioned above, the perception of HIV as primarily affecting African people was partly explained by the fact that African women access government antenatal clinics when pregnant and are tested for HIV while most White women go to private hospitals which do not routinely test pregnant women for HIV:

'When you talk about AIDS, they think about Blacks. Why? Because most of the other races, they can go to private hospitals and private doctors. It comes to the issue of antenatal service.'

Female living with HIV/AIDS

In addition, the socio-economic status of African and White South Africans was also mentioned to explain the perception of HIV as a African disease, with the result that those who have the means are able to afford anti-retroviral treatment and live a healthy life, while hiding their HIV status:

'And also the issue of economic status does count because you find that maybe Whites still have money to buy healthy food and get medication, which makes them to appear healthier than the Blacks.'

Level 9-12 male government employee

Apart from these general findings, the fieldwork findings lent themselves to the categorisation of indicators into two broad areas, external and internal stigma, and into 12 themes across these two areas. The themes of external stigma are avoidance, rejection, moral judgement, stigma by association, unwillingness to invest in PLHAs, discrimination and abuse. The themes of internal stigma are self-exclusion from services and opportunities, perception of self, social withdrawal, overcompensation and fear of disclosure.

4. Indicator findings - external stigma

4.1 Theme: Avoidance

PLHAs reported being avoided by others, often because of a fear of casual transmission of HIV or because of a perception of PLHAs as immoral and dirty:

'Many a time I have had people shout at me, saying "Don't come near me, I am scared of you."'

Male living with HIV/AIDS

Avoidance usually took the form of not wanting to share items with PLHAs such as a chair, utensils, toilets, etc. PLHAs also mentioned experiences of people avoiding spending time with them, or not wanting to be in close proximity to them:

'You sit down [in church] and they all get up and go sit somewhere else.'

Male living with HIV/AIDS

PLHAs reported a feeling of being isolated. In cases were people were generally friendly towards them, it seemed to the PLHAs that they did not want to become too close to them, with the result that they did not have many close friends:

'They are nice to you but they keep their distance. You don't really have many friends.'

Female living with HIV/AIDS

PLHAs reported instances where people refused to touch them or shake their hands and were generally uncomfortable if they were in close proximity. One of the PLHAs interviewed related that as soon as he disclosed his status to someone, it seemed to him as if they are not able to move away from him fast enough. Even people with knowledge of HIV/AIDS avoided people they suspected were PLHAs because of an irrational fear of being infected.

Some PLHAs reported that they felt that they had been reduced to a virus and were defined exclusively by their HIV status. They were seen as a homogenous group of people, based on their HIV status. Whether they were male, female, White, Black, mothers or fathers they were all simply HIV positive:

'People come up to you and say to you, 'I know there are people like you, but I don't want to associate with people like you'. It's not directed necessarily at an individual but the group.'

<div align="right">*Male living with HIV/AIDS*</div>

'Every time they come and visit, they just talk about HIV, as if that's all there is to talk about and all I am is a big virus walking around.'

<div align="right">*Male living with HIV/AIDS*</div>

PLHAs reported having been the topic of gossip. Gossip revolved around a person's HIV status, their possible behaviour or actions which may have resulted in infection, the PLHA's health and speculation that they were dying because they were ill.

4.2 Theme: Rejection

Many PLHAs reported being rejected by their spouses, families, friends and colleagues because of the perception that PLHAs 'deserve' the illness, or the fear that HIV can be transmitted through casual contact:

'You experience it [rejection], especially at home. When you tell your family that you are [HIV] positive they start to chase you away. Like they did to me. They said that I must leave, and must stay away.'

<div align="right">*Male living with HIV/AIDS*</div>

PLHAs described being rejected by partners when they disclosed their status, and being unable to form a relationship with a partner because of the judgemental attitude of people to their disclosure:

'He told me he loved me and I asked him if he's sure and he said yes. Then I tell him I'm HIV positive and he just went quiet for 15 minutes. He doesn't want to be associated with me.'

<div align="right">*Female living with HIV/AIDS*</div>

Some participants reported cases of PLHAs being rejected in their faith communities and being asked to leave their congregations or resign from their positions as faith leaders, after they disclosed their HIV positive status:

'We have records of Imams who have disclosed that they are living with HIV/AIDS and had to go through a 40-day purification period. When they still tested HIV positive they were no longer allowed to practice.'

<div align="right">*Faith leader*</div>

As children were viewed as the primary responsibility of mothers, women living with HIV who had given birth to children who were HIV positive bore the 'burden of guilt' for infecting their children. They themselves experienced stigma, as did their children.

Women mentioned rejection by their partners after disclosing their HIV-positive status and having to care for their children living with HIV/AIDS without the help of the father, who rejected both the mother and children:

'She disclosed to her partner when she was three months' pregnant and he didn't say anything. He then left and never came back again. But when he went away he never came to visit and even now the child is sick he doesn't come to check on the baby in the hospital.'

<div align="right">*Female living with HIV/AIDS*</div>

'She was diagnosed when she was pregnant, the child is now one year and one month. She's fine. But, the father also walked out on her, but now he's terminal.'

Female living with HIV/AIDS

4.3 Theme: Moral judgement

Some participants formed an association between HIV and immoral sex or promiscuity, and therefore deduced a moral judgement of guilt. People who contracted the virus through sexual contact outside the norms of society were seen as 'guilty'. For example, people who fell into this 'guilty' category included those who were unfaithful to their spouses. PLHAs reported that they were often perceived to have been promiscuous and therefore 'guilty' or blamed for their status. According to PLHAs, the immediate assumption people make when they disclose their status is that they are people with 'loose morals':

'HIV/AIDS is connected to sleeping around, to immorality and has got to be recognised as that.'

Congregation member

Some participants reported that how a person contracted HIV informed others' responses to the PLHA:

'I think the immediate thing for most people ... when they hear someone is HIV positive is how did he/she get it? I can't deal with you until I know.'

Faith leader

According to participants, a person was considered 'innocent' if they were passive or powerless in contracting HIV, for example rape survivors, children born to parents living with HIV, and those who contracted the virus through a blood transfusion or needle prick. A person was considered 'guilty' if they contracted HIV sexually outside of marriage. Very few participants challenged the notions of 'innocent victims' and 'guilty victims' of HIV/AIDS even in the PLHA focus groups. However, a few of the PLHA participants challenged the notion of 'innocence' and 'guilt' in contracting HIV, as no one 'deserves' HIV and therefore everyone is 'innocent'. These participants felt that it was not an issue of 'innocence' or 'guilt', but rather the personal responsibility of each person to practise safe sex.

Some male and female participants viewed women as 'innocent victims' of HIV/AIDS because of their physical and social vulnerability in terms of power in negotiating sexual relationships and the use of condoms:

'In general, women, irrespective of their social standing or position in life, when it comes to sex they are basically still subjected to what the man says. And I never hesitate to say that, because we've elevated women to such a high level, but when it comes to sexual issues it seems like men still make the decisions as far as will we use protection or not.'

Male living with HIV/AIDS

'Because I am married to this man, I have to be submissive. I cannot raise my feelings and my ideas when it comes to sex. So some women I find are really innocent victims of HIV.'

Female living with HIV/AIDS

One male participant said that if his partner demanded that he use condoms he would '*beat the hell out of her and she may admit that she doesn't trust me*'.

Women were also viewed as more vulnerable in certain cultures – in particular, cultures that were seen to be very patriarchal:

'When you go to rural areas I think women are more vulnerable, in terms that in some cultures like Venda, Zulu, Xhosa and the like, you find that women don't have the power to have a say when it comes to sexual intercourse ... especially when they are married. Whether the man is HIV positive or not, women just have to submit and give the man what he wants.'

Female living with HIV/AIDS

Some participants viewed PLHAs who had children knowing their HIV status as guilty – this was particularly true where mothers were concerned. Some female participants challenged this view:

'I'm not the only one who is responsible for the child. So why is it only called "mother-to-child transmission"? It should be "parent-to-child transmission". That's what one should look at, because at the end of the day I find AIDS is seen as a thing for women. We're the only ones who pass the transmission to the child. Where did I get the infection? I was not born infected.'

Female living with HIV/AIDS

Female participants reported being called names such as 'bitch' or 'prostitute'.

4.4 Theme: Stigma by association

As a result of the silence surrounding HIV/AIDS and the fear of casual transmission, a culture of suspicion has developed in which people try to identify possible PLHAs through association.

The most commonly suspected symptom of HIV/AIDS was weight loss:

'If we see that you are losing weight, whether you are exercising or whatever, we just assume that you have AIDS.'

Level 1-5 government employee

If the cause of death is not specified, such as a heart attack, car crash or shooting, then it is assumed that the person died of an AIDS-related illness.

PLHAs were accused of lying about their status, as there was the perception that a healthy person could not be living with HIV/AIDS. Other symptoms associated with HIV/AIDS included mental illness, skin conditions, TB, pneumonia and dying young:

'She had TB and people were saying this person has HIV.'

Level 1-5 government employee

It was suggested by participants in the HIV/AIDS co-ordinator group that they themselves face stigma because of the work that they do:

'Sometimes I wonder if people don't think we are all [HIV] positive because we work in this field.'

Some employees did not even want HIV/AIDS posters in the office because they did not want to be associated with HIV/AIDS in any way. Some participants mentioned that wearing HIV/AIDS T-shirts, ribbons or brooches had become stigmatising as some people believed that only people living with HIV/AIDS wore such items. In addition, rape survivors were also stigmatised due to the association between rape and contracting HIV/AIDS. People from certain geographical areas, such as rural areas, were also stigmatised if there was a high rate or a perceived high rate of HIV infection in that area. Another example was the close association between HIV/AIDS and mining communities, where HIV is prevalent. Some participants in the focus groups assumed that all people from Rustenberg (a small mining town) were living with HIV/AIDS.

In addition many PLHAs described stigma which their children or partners were exposed to because of their HIV status. There was also the assumption that PLHA's family members or their partners were also living with HIV/AIDS. Therefore, according to participants a key issue PLHAs need to carefully consider when disclosing, especially to the media, is the effect it might have on family and friends because of stigma by association.

'When people see my children they don't even call them by their names. They just say: "Those are the children whose mother is HIV positive." Sometimes my children come to me crying and saying: "Mama, they say you are going to die."'

Female living with HIV/AIDS

As a result some PLHAs family members encouraged non-disclosure because of their own fears of stigmatisation.

4.5 Theme: Unwillingness to invest in PLHAs

In some cases people claimed that they would not disclose if they learnt that they were living with HIV/AIDS for fear that they would be marginalised within their organisation. This refers to not receiving training and development, and promotion. It also means that they feared they would be given less responsibility after disclosing:

'There is also the perception that if you disclose you are not going to be considered for senior positions. That your supervisor is not going to invest in you. Why should the department invest in you, spend R30 000 on you if they are only going to get 5 years out of you?'

Level 9-12 male government employee

4.6 Theme: Discrimination

PLHAs reported being unable to access services solely on the basis of their HIV status, including life cover and funeral cover, undertakers, medical schemes and blood transfusions. This severely hampered their quality of life and peace of mind:

'Our insurance company cannot give us life cover, so, we will die not having cars, and we will die not having houses of our own because we don't have life cover.'

Male living with HIV/AIDS

'I applied for funeral cover now that I am HIV positive. They rejected my application. I applied again for a second time and it was rejected. I didn't apply for funeral cover again.'

Male living with HIV/AIDS

PLHAs accessing health services did not always receive the same care and courtesy that other patients received. In one case, a woman living with HIV/AIDS was admitted to hospital for meningitis. The matron in charge humiliated and verbally abused her in front of other patients, insisting that they did not provide care for people living with HIV/AIDS.

Staff did not trust workplace HIV/AIDS policies since not many people had openly disclosed their status, thereby 'testing' policy implementation:

'The policy is just there in name only. It's there but nobody bothers to read it and it is not enforced. So its like the policy is not really there.'

Level 9-12 government employee

During the course of the focus groups and interviews with government employees, mention was never made of a formally reported case of stigmatisation.

4.7 Theme: Abuse

PLHAs reported instances of abuse by others because they were perceived as immoral or a threat to the community. Verbal abuse and name calling was a more common form of external stigma than physical abuse. However, at times PLHAs were threatened with physical violence or their lives were threatened:

'Twice I was threatened with my life where people openly told me: "If you don't leave now we will kill you".'
Male living with HIV/AIDS

Other incidents of abuse reported by PLHAs included the beating of wives who disclosed, throwing condoms at PLHAs and being called 'Satan's people' at church.

'When you go back to your man and disclose, tell him you are HIV positive, he runs away, or he beats you.'
Female living with HIV/AIDS

'In your social life people call you names … you're a flipping bad guy, or you're an addict or say I never knew he was in the closet, things like that.'

Male living with HIV/AIDS

According to participants, women are more vulnerable to physical abuse by their intimate partners, as participants mentioned cases of women being physically assaulted by their partners when disclosing their HIV-positive status.

5. Indicator findings – internal stigma

Internalised stigma is influenced by a number of factors.

One important factor is the **environment** in which the PLHA operates, that is, whether it is supportive, hostile or it is an environment where the PLHA thinks he/she is the only person living with HIV/AIDS.

Focus-group participants referred to a supportive environment as consisting of the support of family, partner, community, faith-based groups and non-governmental organisations like NAPWA and the AIDS Training, Information and Counselling Centre (ATICC), which they believed had an immense influence on overcoming internal stigma. The majority of PLHAs emphasised how valuable and important **counselling, information, and support groups** had been in their journey to overcoming the emotional upheaval of discovering their positive status, as well as in starting to live positively. Many stories were shared of how many PLHAs had not received any pre- or post-test counselling for their HIV test. As a result they had been uninformed about the disease and relied on popular knowledge and myths, and on ill-equipped medical practitioners for guidance. Countless PLHAs were informed, upon receiving their results, that they would die within a couple of days. Only a handful could share positive experiences of proper counselling. Many PLHAs believed that it would be very useful for a person who is themselves living with HIV/AIDS to provide pre- and post-test counselling:

'My behaviour – since joining support groups – has changed since getting information on positive living, treatment, skills development and wellness management skills.'
Female living with HIV/AIDS

A second influence is **whether or not the person has accepted their HIV positive status**. This may take time and a person may go through a process of moving from denial to acceptance. Therefore, whether or not a person has accepted their status influences the development of internal stigma.

Past experiences of external stigma also influence internal stigma as experiences of blame, rejection, intimidation, name-calling, exclusion, and isolation may result in a person trying to cope by withdrawing or overcompensating. In addition, past personal views and behaviour toward PLHAs can also influence internal stigma:

'I've never been close to anybody who has got HIV/AIDS, and also, I myself did discriminate against people with HIV/AIDS because I didn't know.'

Male living with HIV/AIDS

Whether the person belongs, or is perceived to belong, to a **group that is already stigmatised,** based, for example, on their race or gender, also influences internal stigma.

Societal associations of HIV, namely the perception that women living with HIV have 'loose morals', and pressure on women (in particular) to conform to norms, can influence internal stigma. As a result, women may experience more discrimination as they are already marginalised. A person's race may also influence internal stigma, for example, Black people are already marginalised because of their race. In addition, it is often women and Black people who are blamed for HIV/AIDS.

Whether the person feels shame, morality or personal responsibility for contracting HIV also influences internal stigma.

Internal stigma also depends on **a person's coping mechanisms.** Some people cope with difficult life situations by withdrawing, others will reach out and be more proactive and assertive:

'But if you are weak and they look you in the eye and you just look away when you are telling them, they'll jump on you, they will discriminate against you ... I think it has a lot to do with you as a person, if you've got the strength to look them in the eye.'

Male living with HIV/AIDS

5.1 Theme: Self-exclusion from services and opportunities

Some PLHAs had chosen not to seek out services or opportunities because of their fear of stigmatisation. These services included support groups, material assistance programmes and clinics:

'Even if there is an offer of a job, I would not apply. It is hard because you think that they will draw blood or look at your urine and see that something is wrong.'

Male living with HIV/AIDS

5.2 Theme: Perception of self

PLHAs seem to be more vulnerable to internalising stigma after being diagnosed with HIV if they have poor personal coping mechanisms, are within a non-supportive environment, and/or have past experience of external stigma and discrimination.

Overall, internalised stigma creates the belief in some PLHAs that they have become **less valuable and worthy** within society because of their 'unclean' state. Should a PLHA be part of an already stigmatised group, this stigma may only reinforce these internalised beliefs about worth. These perceptions reflect society's beliefs and the stigma of the disease. This includes perceiving oneself as less valuable than HIV-negative people, as a disappointment to others, as guilty and immoral, or as a threat to others' health.

Some participating PLHAs described that they felt they had disappointed others because of their HIV status. Internalised stigma can result in PLHAs feeling as though they have brought shame upon their family and community. This sense of having disappointed others is a reflection of the internalised societal beliefs regarding guilt and responsibility for HIV infection:

'I was feeling the fear that I disappointed those people [at church] and then I decided no, the right approach was to disclose.'

Female living with HIV/AIDS

'First I apologised to the church and asked them to take me as I am. And I asked them to give me a second chance to prove myself.'

Female living with HIV/AIDS

5.3 Theme: Social withdrawal

PLHAs may perceive the need to withdraw socially in order to protect themselves (and/or their family and friends) from stigmatisation and discrimination. This kind of self-imposed isolation has led to some PLHAs **excluding** themselves **from sexual and loving relationships**:

'I am no longer involved with anybody.'

Female living with HIV/AIDS

'Although I've accepted the virus myself, the thing is I don't want anyone next to me.'

Male living with HIV/AIDS

Others chose to **only spend their time with other people living with HIV/AIDS**, thinking that they will not stigmatise or discriminate against them. In other words, some PLHAs may withdraw from HIV negative people.

'If you are HIV negative, you are not my friend.'

Male living with HIV/AIDS

The fear of being judged and 'exposed' has led some PLHAs to **not apply for jobs**:

'I have changed my mind-set of how to associate with people. Even if there is a job ... it's hard because you think that they will draw blood or look at your urine and see if something is wrong.'

Male living with HIV/AIDS

Self-imposed isolation can also lead PLHAs to **reject help from others**. According to Daniel and Parker (1993, in Parker & Aggleton, 2002), 'social death' describes a person who no longer feels part of society and is therefore unable to access the support and services they need:

'When I got discharged she was supposed to come to my house to administer the pills, check my blood, everything. I didn't want to see her, I pushed her away and didn't want to speak to her.'

Male living with HIV/AIDS

5.4 Theme: Overcompensation

PLHAs may perceive the need to overcompensate in terms of their behaviour in order to protect themselves from stigmatisation and discrimination. PLHAs may also overcompensate because of internalised stigma.

Other forms of overcompensating behaviour include PLHAS feeling as though they **need to prove** to their faith congregations that they are good people. Some PLHAs have done this by attending church regularly and by asking for an opportunity to prove themselves:

'For me, I would say that earlier I thought I was doing what I thought was godly. I was doing my best to serve God. But when I found out that I was [HIV] positive I said no, I think it was not enough.'

<div align="right">Female living with HIV/AIDS</div>

Some PLHAs may feel that it is important to address the stigma associated with HIV/AIDS in relation to their worth as employees, by **working much harder** than other colleagues as a means of proving themselves.

5.5 Theme: Fear of disclosure

According to most PLHA participants, disclosing their HIV positive status was very difficult, with their greatest fear being judged and rejected from their families, spouses and the wider community. This fear was based on what people have seen happen to others in their communities. As a result many PLHAs do not disclose their HIV status:

'Some PLHAs just cannot find it in themselves to disclose because of the stigma that might follow. They just have so much to lose – the respect of their community and family. Their friends will reject them. So they live in silence. It is an enormous burden to be scared of stigma.'

<div align="right">Female living with HIV/AIDS</div>

When participants who were not PLHAs were asked if they would disclose their status if they were living with HIV, many said they would not due to fear of discrimination at work, for example, not being promoted, being viewed as a burden on the work team, and being seen as less competent and reliable than other staff. Participants were more likely to disclose to their immediate family and partners than at work or in public.

Female participants, in particular, were concerned about disclosing their status to their children. It seemed to be slightly more of an issue for women than for men. The association of HIV/AIDS and promiscuity is one of the reasons for the difficulty in disclosing to children:

'I had a 12-year-old daughter in 1997. It took me almost three to four years to disclose to her because it was not easy. It's just not easy to sit down and tell your child that you've got HIV. It was May 2000. I couldn't face her, I had to write her a letter and say to her this is the situation. But what I did, I first put her on a programme where she was educated, she was informed, she was educated in terms of modes of transmission, and met other women who are living with HIV and they shared their stories with her. So I tried to change all the understanding the attitude and the misconceptions that might come to her mind the day I disclosed to her.'

<div align="right">Female living with HIV/AIDS</div>

'They are still young. I am not ready to tell them that I am sick.'

<div align="right">Female living with HIV/AIDS</div>

'You always think they are still too young, and really at the end of the day there will be no right age…because you being the mother, you will always be protective.'

<div align="right">Female living with HIV/AIDS</div>

6. Government workplace – guideline findings

6.1 Policies

On the topic of HIV/AIDS policies, most participants were aware that there was an HIV/AIDS policy in place. However, there was often ignorance regarding the content of such policies and uncertainty about its implementation, resulting in low levels of confidence in these documents.

6.1.1 Distrust of policies

The content of HIV/AIDS policies is not well known to employees, and as a result government employees do not place much trust in these policies. It appears as though **distrust** of policies was an aspect of the broader issue of the low levels of trust that officials have in public sector leadership. The general consensus was that while the policies were in place, there remained serious concerns about implementation. Many employees felt that the policies had not yet been tested in sufficient cases of HIV/AIDS. As a result they would not themselves disclose, as they were unsure that the protection outlined in the policy would be forthcoming:

'Sometimes we don't know the HIV policy. How can I disclose if I don't know of the policy? It's part and parcel of the benefit. We cannot expect our people to come forward and disclose.'

Level 6-8 female government employee

It was believed that the problem of policies not being widely implemented, and hence not being 'tested' in a way that would build trust, was partly due to the fact that employees were not aware of the relevant workplace policies:

'I think we have a policy but as to how effective it is, [that] is something else. The policy is just there in name. You find that it's there, but nobody bothers to read it and it is not enforced anywhere. So it's like the policy is not really there.'

Level 9-12 male government employee

Government settings also faced the problem that there were very few PLHAs who have openly disclosed, and as a result there has been little opportunity to implement the policies:

'We have these policies sitting there gathering dust because we're not implementing them. We don't have people coming forward, so we cannot implement the policies and see whether or not they work.'

Level 6-8 government employee

There was also the perceived problem of bureaucracy. A participant from the Department of Correctional Services mentioned that it was difficult to adapt policies so that they were capable of providing assistance to PLHAs. Speaking of an employee assistance programme (EAP) professional he said:

'The people go to him and he assists them as far as possible but then he runs into red tape and it takes months, years to get rid of that red tape'

Level 6-8 government employee

6.1.2 Issues of confidentiality

There were clear indications that **confidentiality and trust** were not high in the public sector. In general, the focus-group participants did not trust that their supervisors or colleagues would not disclose their status to others.

EAP professionals were not trusted to keep information confidential: *'People do not trust them. They think they are going to run around shouting the news to everyone. It becomes a wonderful topic of conversation'*. The same applied to the medical practitioners within the Departments. A participant mentioned that the people who had disclosed within the Department *'are petrified that the medical practitioners will tell others'*.

People's tendency to **gossip** about those who are living with HIV/AIDS was frequently mentioned. As a result, employees were concerned that their colleagues would gossip about them behind their backs should they learn that they were living with HIV/AIDS:

'The problem lies in telling this person and she will tell somebody else and it will go around. That is the main problem.'

Level 6-8 government employee

There was also much concern that management has **access to employees' private files** and in that way could learn of an employee's status, even without being told. Some were worried that by looking into the details of employees' medical aid insurance, managers would be able to ascertain the status of individuals:

'I wouldn't disclose at work. Managers have a way of knowing your status before you have even found out. I'm even afraid to go to the hospital because my manager will know before me if I am positive or not. So, I wouldn't tell them. I wouldn't even let them know I'm sick.'

Level 1-5 government employee

6.2 Leadership

According to the participants, there was an erosion of employees' confidence in senior management's leadership in terms of dealing effectively with HIV/AIDS. This was the result of the perceived poor support and commitment from senior managers to HIV/AIDS issues, the perceived ignorance of senior managers regarding issues of HIV/AIDS, the perception that HIV/AIDS issues has been shifted to the staff within Human Resources, and poor communication between senior managers and HIV co-ordinators.

6.2.1 Poor senior manager commitment to HIV/AIDS

One of the overarching themes to emerge from the workplace focus groups was participants' perception that there was poor support from the upper echelons of the departments regarding HIV/AIDS issues. Senior managers – namely director-generals and directors – were perceived as unsupportive of HIV/AIDS interventions and uninterested in related policies:

'Most times when you go to workshops you will not find managers there. You will only find lower level people there. In most cases managers do not participate.'

Level 9-12 government employee

Government employees' feelings of alienation from management were strong and pervasive with regard to the issue of HIV/AIDS. One participant from the senior management group described the relationship between staff and management as: '*senior managers do not give their support. They are always not there. It is always "them" and "us", with a vacuum in between*'.
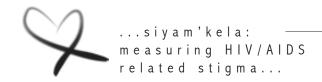
The approach adopted by senior management had the effect of communicating to staff that they '*couldn't be bothered*' and that '*It is not our problem – it is somewhere out there*'. Participants believed that it was very important for staff to see senior managers supporting HIV/AIDS-related events, as this would set an example for the staff who reported to them.

One participant believed that the poor commitment from managers in the public sector was in part the result of poor leadership provided by the minister of health. He described the situation as follows: '*She's not taking this up seriously. So why would our director- generals take it up seriously? Why? She should be in charge, but all she says is "don't use AZT. Use garlic!"'*

There was a perception that HIV/AIDS programmes were about keeping up appearances, rather than affecting genuine change. It was felt that managers '*would like to see somebody sitting in a chair at that desk, doing the job and keeping up appearances for the department and their office*'.

6.2.2 Senior managers perceived as ignorant and uninterested in HIV/AIDS issues

Government employees – particularly the HIV/AIDS co-ordinators – believed senior managers to be ignorant of HIV/AIDS issues, which further eroded their confidence in their departments' leadership. This was based on the perception that senior management did not support or get involved in HIV/AIDS issues and policies and as a result were not informed on the topic.

In terms of managers' perceived ignorance about HIV/AIDS, one HIV/AIDS co-ordinator claimed that: *'They are clueless about HIV/AIDS. They have no idea. They don't even know what HIV stands for!'*

6.2.3 Responsibility for HIV/AIDS strategy shifted to human resources directorates

The strategy adopted for managing HIV and AIDS was criticised by the HIV/AIDS co-ordinators and managers (Level 9-12). In particular, they felt that the managers tended to shift the responsibility for such issues to the human resource directorates.

It was mentioned that senior management did not view it as their responsibility to give input into HIV/AIDS policy, as it is viewed as the responsibility of human resources. The importance of input from line managers into the development of HIV/AIDS policies was emphasised:

'When you ask senior managers for their input they say: We have better things to do than give input on that policy. So they think that it is not their responsibility. They do not think that they are part and parcel of the process and that it is important as a line manager to give input in terms of the HIV/AIDS policy. And if they do not really see the importance of such a policy and giving input, it will remain a paper.'

Level 9-12 government employee

6.2.4 Poor communication between HIV/AIDS co-ordinators and senior management

The source of senior managers' information regarding HIV/AIDS issues and developments was questioned. In particular, there was concern regarding the information managers used for their reports, since they do not directly interact with the HIV/AIDS co-ordinators to obtain the relevant facts.

6.3 Interventions

6.3.1 Current interventions

This examination of workplace findings will inform the development of workplace-specific guidelines. It is useful to review interventions that have been attempted to address HIV/AIDS in general, and stigma in particular.

National government departments are currently involved in a range of HIV/AIDS programmes including:

- education
- counselling
- awareness raising
- special events
- prevention
- support groups
- contacting external consultants to give talks on HIV/AIDS.

6.3.2 Formal HIV/AIDS messages

According to senior managers within national government, formal HIV/AIDS messages communicated by their departments included:

- 'condomise'
- 'national government provides a support framework'
- 'you will not be discriminated against if you are HIV positive'
- 'support people living with HIV/AIDS'

- ■   'HIV/AIDS is real'
- ■   'we can do something if we know your status'.

These messages were included in the posters, pamphlets and other materials distributed within national government departments.

There were, however, several key issues that hampered these programmes, including apathy among employees regarding HIV/AIDS issues, limited resources and competing departmental demands.

6.3.3 Apathy amongst employees concerning HIV/AIDS issues

Participants reported apathy among employees when it came to issues of HIV/AIDS. This was partly because they were bored with the topic, and partly because they viewed HIV/AIDS as someone else's problem. As one of the HIV/AIDS co-ordinators who had organised HIV/AIDS-related events in the past mentioned,

'If I organised a meeting and there was no food, then people weren't interested in what they were going to hear. They were only interested in what they were going to eat. And that made it difficult. People aren't interested.'

Level 6-8 employees were very vocal about generalised lack of interest and the role it played in limiting the impact of HIV/AIDS programmes. They mentioned that most employees believed that HIV/AIDS did not concern them and that it was someone else's problem. This attitude towards the pandemic influenced public officials' perceptions of whether or not they would tell others if they were living with HIV:

'I also won't disclose to my colleagues because I know from experience that they think it's a joke. It's not something to take seriously. When you really start talking about it, they just start laughing. They say that it doesn't concern me.'

<div align="right">Level 6-8 government employee</div>

A further challenge in running interventions has been employees' **fear of stigmatisation and discrimination**. As a result, very few employees have disclosed their HIV status. A suggestion for overcoming the lack of interest in HIV/AIDS was to include other health- related topics, which would draw people to educational talks.
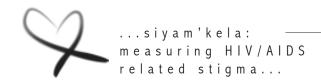
HIV/AIDS co-ordinators also complained that they only have limited resources and have a range of other competing demands to manage, since HIV/AIDS is only one of many other responsibilities they have to tackle within already challenged departments. Issues of budgetary constraints also affected the impact that HIV/AIDS interventions were able to have:

'There are so many competing demands in the departments. We have our core business, and now this added challenge of HIV/AIDS and it becomes overwhelming. All these competing demands – and now HIV is challenging us further! We don't have the capacity to run programmes effectively. I'm just one person for nine provinces.'

<div align="right">HIV/AIDS co-ordinator</div>

Participants were critical of the current awareness-raising strategies being implemented in their departments. A common concern was that the interventions were not having the intended effect of changing the attitudes and behaviour of employees. As a result there was growing disillusionment with the efficacy of training as a means of achieving this end.

There was also some dissatisfaction with the way in which training was rolled-out. The training was generally lecture-based and this was criticised as lacking creativity. In addition, there was the complaint that only a select group of people were sent for training, preventing a broad base of informed staff members.

One of the HIVAIDS co-ordinators also raised the concern that the problem with lecture-based awareness interventions is that the approach does not encourage people to ask questions about the sensitive topic of HIV/AIDS. It was therefore suggested that interactive sessions would be more effective. This was especially true for sessions conducted by PLHAs, as this added an interest value for employees and gave sessions additional credibility.

With regard to HIV/AIDS messages, the implicit assumption that HIV/AIDS awareness starts and ends with the distribution of condoms was criticised.

'The message that I get is that at the end of the day people think that the responsibility begins and ends with a full condom machine. They don't ask anything more.'

Level 9-12 male government employee

7. Faith-based organisations - guideline findings

7.1 Policy

7.1.1 Issues of confidentiality

Lack of confidentiality was a concern raised by the faith group participants in the *Siyam'kela* study. In particular, there was criticism of how faith leaders deal with people's disclosure of their HIV positive status. The issue was raised that there are no confidentiality regulations within faith groups, other than those related to confessions in the Catholic Church, to offer standards and guidance:

'How do we deal with confidentiality? I don't know, because we are not good at it!'

Faith leader

A faith leader spoke of the experience of a friend who disclosed to church leaders, and of his own personal experience of disclosing his status within his church. In the case of his friend, he went to tell his *dominee* (minister) who said he thought the council should be told, '*and they were so shocked by [the news] that they needed to share it with their wives, who were so shocked that they just felt that they needed to share it with their friends, who were so shocked that they needed to talk about it at the tea party'*.

The faith leader's own experience was not much different – he told his bishop who told the chaplain who shared it with his wife, who spread the news further.

Faith community members voiced similar concerns about trust and confidentiality within their faith communities. One member mentioned how a Reverend announced the death of a congregational member and included the fact that the person had died of AIDS.

It was highlighted that the issue of confidentiality is a particular problem for faith communities which do not practice confession between priests and community members. The problem was highlighted by one participant and described as follows:

'In churches where confession is not practised there is no respect for private sensitive information. We think that we need to share [information], that's where the problems come.'

Faith leader

In the light of this it was emphasised that every faith community should come up with policies regarding HIV/AIDS and confidentiality.

7.2 Leadership

Focus-group participants felt that some faith leaders were **ill equipped** to deal with people who turned to them for advice on issues related to sex, safer sex practices or disclosure of their HIV positive status.

In one example, a faith leader spoke of an acquaintance who disclosed to his bishop that he was HIV positive, '*The problem was that the Bishop kept quiet. The only advice was he gave was not to speak to anyone else. There is no support.*'

Certain faith groups reported a **climate of denial regarding HIV/AIDS issues** affecting their faith groups. This was especially the case in more middle-class Christian congregations, as well as the Muslim faith community, which did not believe that HIV/AIDS was a problem in their communities.

The realisation and acceptance by faith groups of the possibility of the existence of HIV/AIDS in their communities was seen as the first required step in creating a safe and welcoming environment for those who are living with HIV/AIDS to disclose. However, it was reported that certain faith leaders were not acknowledging that HIV/AIDS was affected their faith communities:

'*My peers, they feel that it [a support group] is not of importance, because we live with the concept that our community is not infected, but meanwhile many are living with it ... They are in denial.*'

Faith leader

7.3 Interventions

Faith groups had implemented a wide range of interventions. Where no interventions were in place, plans were being developed to deal with HIV/AIDS issues within faith communities. The main focus of the interventions and programmes in place was to provide care and support to PLHAs. The support given can be categorised as creating a supportive environment and giving material support.
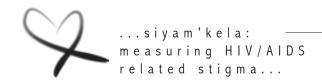
7.3.1 Creating a supportive environment for PLHAs

With regard to creating a **supportive environment**, faith leaders placed a lot of emphasis on spreading a message of acceptance. One faith leader mentioned that the church could facilitate the emotional healing of a person who has learnt that they are HIV positive by providing a '*humane and loving*' environment through, for example, pastoral counselling and prayers. This would enable PLHAs to move from '*bitterness to acceptance and understanding*'.

The involvement of faith leaders and faith community members was recognised as critical in order to play this facilitating role. One leader described how the church had played a supportive role for someone living with HIV/AIDS: '*I think when the church knows and the church gets involved [then] I think it does make a difference. I think of one particular case where there definitely was a movement closer to God. But as I say, it normally starts with a lot of bitterness – the same kind of thing when there is a tragedy or when you hear you've got cancer and its terminal.*'

One practical way of creating a supportive environment was by forming support groups and prayer groups. A faith leader explained the role of these care groups as '*the care-givers identify the people, visit them, give them food and do whatever they can*'.

Faith groups were responding to the specific needs of PLHAs in terms of **material support** as well. Nutritional programmes and the distribution of food parcels were also mentioned. These interventions also focused on providing support to PLHAs' dependants and families. For example, there were plans to

provide assistance to secure social grants for orphaned children. In addition, support groups were in place for faith community members who were infected and affected by HIV/AIDS, as well as pastoral care.

'Whenever they speak in church about their experience, we usually end the discussion by asking the person, "What do you want us, as the body of Christ to do in response to what you are saying?"'

<div align="right">Faith leader</div>

In some cases it was noted by participants that members of their faith cared for those living with HIV/AIDS by providing them with food parcels and clothes. Where possible, faith groups were attempting to respond to the health care needs of PLHAs in the form of home-based care or establishing hospices in the community. This was, however, dependant on the funding received and having relevant trained personnel at their disposal. One example noted was a church in Umlazi. With assistance from a local clinic it was able to provide AZT to congregational members who were living with HIV.

7.3.2 HIV/AIDS training initiatives

Few **training initiatives** were reported in the focus groups. The training initiatives, which were reported tended to focus on training faith leaders to be sensitive to issues regarding HIV/AIDS. This included how to respond to HIV/AIDS in their faith communities in a compassionate and non-judgemental manner, thereby removing the perception that HIV/AIDS was a sin:

'In terms of specific training it would be around trying to understand the crisis and the response to HIV/AIDS. And particularly around notions of deserving the disease.'

<div align="right">Faith leader</div>

While the main thrust of the interventions was geared towards the welfare of PLHAs, there were some awareness-raising interventions in the community. These **awareness programmes** were not only geared towards specific denominations but targeted the community at large.

7.3.3 Faith-based services

With regard to **faith-based services**, according to participants very few had changed in response to HIV/AIDS. Only pre-marital counselling was mentioned as different, in that HIV/AIDS was now included as a topic in counselling sessions. Some participants noted that HIV/AIDS was not discussed at Sunday school and confirmation classes. In most cases, faith communities had responded to HIV/AIDS by including the topic in sermons set aside to focus on HIV/AIDS or inviting PLHAs to share their stories with their congregations. However, HIV/AIDS was often not dealt with outside of World AIDS Day and other AIDS-specific events.

7.3.4 Prevention

Faith-based organisations continue to debate what constituted **appropriate HIV/AIDS prevention messages**. While there was uncertainty regarding what the content of prevention messages should be, the caring and support role of faith-based communities in relation to HIV/AIDS was broadly accepted. As noted by one respondent, the church was struggling with how to deal with prevention and had therefore found a safer response in providing for PLHAs' welfare, in line with the traditional role of the church as a 'carer':

'It's a very difficult one. I don't know for how long we will be emphasising the problem of care and support and not on prevention. Because I think churches tend to want to address caring for the sick. I think that is important, but what do we do to make sure we have methods that will help prevent the spread of the virus?'

<div align="right">Faith leader</div>

The overarching prevention messages conveyed by faith groups were in line with religious teaching, that is, encouraging abstinence before marriage and faithfulness within marriage. However, it was recognised that faith groups were faced with challenges in following this prevention strategy; as a result some questioned whether messages of abstinence and faithfulness adequately accounted for the issues facing communities.

Faith groups were struggling with prevention messages when faced with the realities of sexuality in their congregations and among youth in particular. Difficult questions and issues were raised in awareness and prevention efforts and faith leaders were uncertain about how to respond to youth in such cases. For example, one faith leader was uncertain on how to respond to a 13-year-old girl asking what she should do in the case of an allergy to condoms. There is concern about the best way to handle prevention in the context of religious teachings.

'Is it really possible for them to totally abstain? I think there are a lot of things that we need to discuss as the church and see what actually works.'

Faith leader

Another challenge facing faith groups include the best strategy to deal with prevention within marriage. The feasibility of merely advocating faithfulness and rejecting the use of condoms in marriage was questioned. While some faith groups rejected the use of condoms, others felt that the occurrence of unfaithfulness in marriage was a reality that should be reflected in faith groups' responses to HIV/AIDS. Certain faith groups, in light of the high rate of infection among married couples and the belief that some women were disempowered in intimate relationships, encouraged married women to insist on the use of condoms to protect themselves from infection.

7.3.5 Association of sex, HIV/AIDS and sin

Doctrinal teachings make it difficult to deal with HIV/AIDS in a non-stigmatising manner, and at times the prevention messages of faith groups were presented in a punitive and discriminatory manner:

'Don't get the imams to talk about it. They speak so much nonsense and spew prejudice. Better they shut up instead of saying anything.'
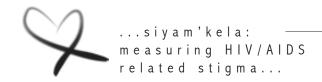
Faith leader

The challenge for faith groups was how best to non-judgmentally respond to prevention, while upholding their religious teachings. Faith groups were attempting to mitigate stigma and trying hard to get the message across that HIV was not a sin. However, when speaking of prevention strategies, sex before marriage was condemned a sin and as a resultant, those who were single and sexually active were seen as sinners. HIV/AIDS was closely associated with sex in faith communities. Faith groups grappled with how to reconcile the message of compassion and acceptance towards those living with HIV/AIDS, while holding onto the teaching that sex outside of a marital relationship was a sin and forbidden.

'The problem with associating it [HIV] with sex is that the Church sees sex as a sin, particularly if it's outside the confines of marriage. If you contracted HIV/AIDS it must have been through sex. It must have been unlawful sex. Therefore you are a sinner and it's a punishment from God. That is where much of the stigma originates. From our own teachings.'

Faith leader

7.3.6 Not dealing sufficiently with issues of sexuality

Some participants recognised that prevention strategies could not be a matter of simply advocating 'abstain from sex', but should also encompass providing knowledge about sex and a healthy sexuality.

For example, the point was made that sex could not be viewed as a taboo topic in the church any longer and open discussion about sexual issues had to be encouraged.

'We asked ourselves, are we doing enough for the young people in terms of human sexuality or youth sexuality? If we are quiet about sex and sexuality … then we are not dealing with the issue.'

Faith leader

7.4 Partnerships

Faith groups were initiating partnerships and networking with other faith groups who had established programmes or interventions, and with organisations working in the field of HIV/AIDS. There seemed to be recognition that collaboration and partnerships with other organisations and groups were vital in effectively responding to the needs of PLHAs. This included sharing resources and information. Faith groups were also making use of trained individuals in their congregations to inform their response, for example, working with service providers such as hospices to provide training in home-based care, or creating partnerships with social services:

'We are looking to partner with as many people who want to get involved as possible, simply because we believe that it's in collaboration that we're going to accomplish this.'

Faith leader

8. PLHAs interacting with the media – guideline findings

8.1 Consultation

PLHAs felt that they should be consulted to assist with awareness messages and storylines for television and radio programmes. There was strong disapproval of programmes using people who were not living with HIV/AIDS to provide information on living with HIV/AIDS. This role was seen as more effectively dealt with by people living with HIV/AIDS, as it was better to hear it from the 'horse's mouth'.

'What I think could be causing a lot of trouble is a person not living with HIV/AIDS speaking on behalf of those of us that are HIV positive.'

Male living with HIV/AIDS

PLHA participants in the focus groups believed that there was a lack of empowered PLHA voices in the media.

8.2 Language and messages

A concern for PLHAs was the terminology the media used to describe PLHAs – as 'sufferers' or 'victims' – which in itself was disempowering. Participants living with HIV/AIDS believed that the media perpetuates certain perceptions of HIV/AIDS and stereotypes them. Specifically, PLHAs were represented as sick and dying, promiscuous and / or as Black women.

With regard to messages conveyed by awareness campaigns and the approach taken in interventions, PLHAs felt that prevention messages that used fear or war terminology, were in fact contributing to the problem of HIV/AIDS stigma:

'Those people said AIDS kills. I believe that that type of fear management, which is dysfunctional, completely dysfunctional, has a lot to account for when it comes to the current situation.'

Male living with HIV/AIDS

It was also suggested that the popular use of war terminology in activism and awareness campaigns, mobilising to 'fight' against HIV/AIDS evokes contempt for HIV/AIDS and feeds into stigma.

8.3 Agency

Some PLHA focus-group participants had had empowering interactions with the media, while others had had disempowering experiences. PLHAs reported experiences where the media selected aspects of their stories to report to make the story more newsworthy, and changing the story by selecting information that fitted the perspective they wanted focus on. For example, one PLHA interviewed mentioned that the media might focus only on how a person contracted the virus.

'They actually only showed [my story] from the side they wanted to show. [The show] dealt with moral issues. The topic was whether [HIV] is a punishment of God or not. That was the direction they were going in and some of the things that they were saying, it seemed that they wanted people to believe that it is a punishment.'

Male living with HIV/AIDS

Supporting or empowering practices mentioned included PLHAs interacting with the media practitioner before the interview and having the opportunity to edit and review programmes and articles before they were printed or aired. Other empowering practices involved PLHAs being able to review questions before an interview, which allowed them to select those questions they were comfortable with and to rehearse their answers.

8.4 Intrusiveness

Most PLHAs reported being asked very personal questions in interviews about their current sexual relationships, partners and sexual practices, such as: Do you use protection when you have sex? Have you disclosed your HIV-positive status to your sexual partners? How were you infected with HIV?
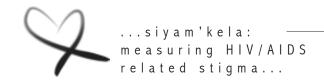
8.5 Disclosure

'You need to decide when you disclose, whether you are going to tell everything. I am talking about public disclosure, not disclosing to a friend, or a buddy or a family member. Before you disclose you need to come to terms with what you have done, because it's no use telling a lot of lies to people.'

Male living with HIV/AIDS

This relates to difficulties PLHAs reported in disclosing to the media, as one needed to be prepared for the possibility of experiencing stigma and discrimination after publicly disclosing. It seemed that the PLHAs who had accepted their status, tended to feel more ready and comfortable when they disclosed their status publicly.

'The difficult issue is obviously to deal with what comes at you, because if you disclose you obviously open yourself to all sorts of abuse. Whether it be physically, whether it be verbal, but you open yourself to that and you must be prepared.'

Male living with HIV/AIDS

8.6 Suggestions made by PLHAs

Participating PLHAs gave the following advice to PLHAs who intend to interact with the media. They should:

- decide which issues they are comfortable discussing with the media
- be assertive when interacting with the media concerning which questions they are prepared to answer
- ensure that their story is told in the way they intended it to be
- see the questions beforehand in order to prepare answers
- interact with the interviewer before the interview
- ensure that they read the article before it is printed
- decide in advance what they are comfortable with disclosing
- come to terms with their status and past experiences if they are to disclose publicly.

9. Conclusion

This report reflects a 14-month process and includes the work and input of many dedicated individuals who are committed to addressing HIV/AIDS stigma.

The content from the 23 focus-group discussions emerged as 12 inter-connected themes, broadly categorised as external and internal stigma. The overarching themes common to all forms of external stigma were of excluding PLHAs, and judging them as less valuable than people who are HIV negative. These themes emerged from the thoughts and experiences both of people who are living with HIV/AIDS, and those who are not necessarily HIV positive but located in faith communities and national government departments.

The various manifestations of internalised stigma are the response of internalising the negative responses of others. The themes included PLHAs removing themselves socially and from services so as to avoid rejection, or because they considered themselves less valuable as a result of their infection. These themes emerged from the experiences of 81 PLHAs.

The themes to emerge from the above discussions were significant in that they formed the basis for the development of a set of indicators for measuring stigma-reduction programmes, as well as a set of guidelines for PLHAs (with respect to their engagement with the media), for faith communities and for national government departments regarding how they could mitigate HIV/AIDS stigma in these three settings.

This research project has enriched all who have worked on it. Thanks are due to all of the participants for their valuable contributions to the *Siyam'kela* Project. Special thanks are due to the many people living with HIV and AIDS who shared their stories of overcoming difficulties and moving towards personal acceptance.

It is hoped that as a result of the participatory nature of this project, the resulting family of reports[4] will be interesting and useful, and will assist in mitigating HIV/AIDS stigma effectively.

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[4] See POLICY Project website (http://www.policyproject.com/siyamkela.cfm) for the available reports:
1. HIV/AIDS related stigma: A literature review
2. Examining HIV/AIDS stigma in selected South African media – January – March 2003: A summary
3. HIV/AIDS stigma indicators: A tool for measuring the progress of HIV/AIDS stigma mitigation
4. Tackling HIV/AIDS stigma: Guidelines for the workplace
5. Tackling HIV/AIDS stigma: Guidelines for faith-based organisations
6. Tackling HIV/AIDS stigma: Guidelines for people living with HIV/AIDS who interact with the media
7. Promising practices of stigma mitigation efforts from across South Africa: Reflections from faith-based organisations, people living with HIV/AIDS who interact with media and HIV/AIDS managers in the workplace

Appendix 1

Breakdown of participating national government departments					
Departments	Director-generals or nominees	Level 9-12	Level 6-8	Level 1-5	HIV/AIDS co-ordinators
Agriculture	x	x	x		x
National Treasury	x	x		x	x
The Presidency		x	x	x	x
Public Service Commission	x	x	x	x	x
SAPS	x		x	x	x
Land Affairs	x	x	x		x
Correctional Services	x	x	x		x
Housing				x	x
Justice	x				x
Arts & Culture		x		x	x
Science & Technology	x		x	x	
Social Development		x			

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